

Agenda
Genetic and Metabolic Diseases Advisory Committee
October 23, 2019
10:30 am-2:00 pm
Crowne Plaza Chicago SW Burr Ridge
300 S Frontage Rd
Burr Ridge, IL 60527
Ph 630-325-2900
Contact: IDPH Staff 217-785-8101

- I. Welcome and Introductions
- II. Vote on Bylaws
- III. Vote on May 21, 2019 meeting minutes
- IV. Committee Member status: current, pending, vacancies
- V. IDPH Reports
 - A. Newborn Screening Laboratory
 - 1. Less than 24-hour sample collection
 - 2. ALD screening
 - 3. Projected SMA implementation timeline
 - 4. Saturday operations
 - 5. NBS fee increase
 - 6. GAMT legislation
 - 7. Legislative Rules
 - B. Newborn Screening Follow-Up Program
 - 1. SMA designated consultants
 - 2. Saturday operations
 - 3. UPS courier shipping
 - 4. Grant funding
 - C. Early Hearing Detection and Intervention Program
- VI. Other Reports
 - A. Newborn Screening and Laboratory Subcommittee
 - B. Newborn Screening Cystic Fibrosis Collaborative-no recent activity
 - C. Newborn Screening Hemoglobinopathy Collaborative
 - D. Severe Combined Immune Deficiency Newborn Screening Collaborative-no recent activity
 - E. Newborn Screening Expansion Subcommittee-no recent activity
- VII. Reports from Partners
 - A. Norton & Elaine Sarnoff Center for Jewish Genetics
 - B. Sickle Cell Disease Association of Illinois
 - C. Illinois Society of Genetic Professionals
 - D. Sudden Infant Death Services of Illinois, Inc.
 - E. Division of Specialized Care for Children
- VIII. Other New Business
- IX. Next Meeting Date
 - A. TBA
 - B. Emergency contact information
- X. Public Comments